Personality Disorders and the Dying Experience: Reflections on Pastoral Care

Gretchen Thompson

Dying is huge. Whether the process begins in an ICU, ER, a hospital room, a nursing facility, a hospice, or the familiarity of one's home; whether it approaches rapidly, slowly, violently, peacefully, predictably, or quite unexpectedly; it is a sacred and often demanding journey, perhaps the most monumental of all human experiences.

Dying can be a time when spiritual transformation already has so much natural momentum that chaplains face a somewhat distinctive task. Often, it is too late to help individuals to reframe theological frameworks, belief systems, habits, behavior patterns. The dying process itself may reframe—sometimes dramatically—any or all of these. The chaplain's role may be simply to provide a comforting presence.

Spiritual comfort at the time of dying often springs from two human capacities: hope and trust. Across cultural and religious variations, despite age or gender, these two capacities can serve the dying process tremendously. They help to fend off terror and panic, or at least to place these painful emotions in a larger and more redeeming context. They can generate the courage needed for reconciliation, forgiveness, and closure, leading the individual to an invaluable calmness and peace of mind. They provide great sustenance as the individual is forced to endure longer and longer periods without physical expression. And perhaps most important, from a spiritual standpoint, they provide connection to both holiness and future. Trust helps us as humans connect to that which is greater than we are, and to be sustained by it. Hope helps us to believe that this connection will be there for us in the future, even if we cannot, from our present vantage point, comprehend or imagine how that will occur.

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If we as spiritual caregivers can evoke any degree of trust and hope in the dying patient, we are doing well. Typically, we do this in many ways, utilizing various techniques: active listening, prayer and ritualization, naming and honoring, creation of time and space for life review and/or reconciliation, music, touch, expression of compassion, witness, scripture, support for loved ones and family, reconnection with sources of strength. Each of us has our own list, and each list is the result of years of training, experience, and honed intuition.

This article focuses on pastoral care to the dying in terms of evoking trust and hope. It deals specifically with patients whose unique needs regarding hope and trust are frequently misunderstood or overlooked: those people with personality disorders.

It addresses two basic questions: How can we best serve those who enter into the dying process with personality disorders? How can we help them find hope and trust as they set out on this often overwhelming journey? Though it is written from the perspective of a hospice chaplain, the concepts are applicable to other settings in which the chaplain encounters people suffering from personality disorders and seeks to establish an environment of comfort, hope, and trust.

What is a personality disorder

M. Scott Peck provides the following global explanation of personality or character disorder—the terms are used interchangeably—in his recent book Denial of the Soul:

It can be helpful to look at both neuroses and character disorders as disorders of responsibility. As such, they are opposite styles of relating to the world. Whenever she is in conflict with the world, the neurotic tends automatically to think it is her fault. Whenever he is in conflict with the world, the character disordered person tends to assume it is the world’s fault.

A significant portion of our lot of existential pain throughout life is the anguish of continually and accurately discerning what we are and are not responsible for. It can be seen that both neurotics and those with character disorders avoid this existential anguish.¹

He goes on to say that while neuroses often cause acute internal suffering for their bearers, personality disorders—also painful for their bearers—may cause profound pain in the world around them because accusations and blame are predictably aimed outwards, no matter what the circumstances.

If you feel as though everything is your fault i.e., neurosis, you may seek help from a therapist or other care provider. This leads to diagnosis. On the other hand, if you think everything is the world’s fault, i.e., personality disorder, you simply try to endure a world that you perceive as indifferent at best, cruelly hostile at worst, and are less apt to seek therapy. Thus, people with personality disorders often remain undiagnosed.

Though statistically representative of up to 19 percent of the general population, such people often are unidentified.² Even when they are diagnosed, they rarely self-describe by naming their specific disorders.

It is not uncommon for patients to say, “I’ve struggled with schizophrenia since I was a young adult,” or “They say I’m bipolar,” or “I’m an alcoholic in recovery for five years now.” They are very unlikely to say, “I have a histrionic personality disorder,” or “I think I may be borderline,” or “Call me a narcissist.”

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association, personality disorders (Axis II) are distinct from, and yet can coexist with, Axis I disorders such as depression, psychosis, schizophrenia, bipolar disorder, and post traumatic stress syndrome.³ In fact, they can hide behind or look like these other conditions, making them even harder to recognize.

Research suggests that these disorders have both genetic and environmental origins. For instance, though some studies indicate a very strong correlation with childhood trauma, neglect, and sexual or emotional abuse, recent studies of twins and other research point to biological and neurochemical correlations as well.⁴

Although the DSM identifies ten different forms of personality disorder, grouping them into three broader categories or clusters, all tend to manifest in the following two ways.

Inflexibility

People with personality disorders are often rigid or inflexible, lacking the ability to adapt or self-correct. This is not their fault per se; it is simply the way their personalities, for reasons both environmental and genetic, have become formulated over several years. With reference to
Scott Peck's explanation, because of their more outward focus, they have a decreased capacity for self-reflection that can seem very unusual to those who are adept at discerning a given context and responding to it in kind.

Psychologist Gregory Lester, who has done some excellent work translating personality disorders into practical terms specifically for health clinicians, gets at this quality through the metaphor of piano playing. He posits that for most of us the developmental process of growing up involves learning to adapt and adjust to the world around us. Like piano performers, we learn a wide repertoire of pieces, become adept at many, and, in our maturity, play the right piece in the right context with little effort. At a wedding, for example, the skilled pianist will play joyous music; at the funeral, dirges; at the ball park, a national anthem.

Likewise, when things go well for us, we feel happy and celebrate. When we experience loss, we grieve and offer comfort to others. Injustice angers us, and we act to correct what is wrong. In other words, we respond to our world in ways that show we are basically in sync with it, that we discern its changes and variations with some accuracy.

According to Lester, someone with a personality disorder functions more like a player piano. This individual has only one or two tunes and plays them again and again, starting up the same roller over and over, no matter what the context. It is as though the capacity to interpret and adapt is largely missing. Thus, those with a paranoid personality disorder have a distrustful player piano tune, which is played out at work, at home, at the wedding or the funeral or the ballpark, in the store.

On the other hand, those with a narcissistic disorder will play the tune of their own superiority wherever they go. It does not matter whether they are CEOs in board rooms, librarians in the stacks, or cabbies in rush hour traffic. They understand themselves as the center and the best, and no amount of feedback from the environment is likely to change their tune. Indeed, this is the only tune they know, and often the only one they can learn.

Unlike depression or other diagnoses more responsive to medication and therapy, personality disorders are, by their very nature, fairly intractable. Recent insights in psychiatry and cognitive therapy are beginning to offer new hope, but at this point, the treatments are lengthy, intense, and, sadly, often unsuccessful. As a result, such therapies would rarely be appropriate to enlist in relation to the dying process because of time limitations.

For detailed information about current modes of diagnosis and treatment, see Jeffrey E. Young, Cognitive Therapy for Personality Disorders: A Schema-Focused Approach, 3rd Edition. It is clear, yet comprehensive, and includes a diagnostic questionnaire as well as a whole section for clients.

**Difficulty in relationships**

A person who can play only one or two tunes will do fine in a few specific contexts, but poorly in many others. Sustained relationships can prove the most challenging of all, for they often require the widest range of adaptability over time.

People with personality disorders may struggle profoundly with deep or intimate connections, leaving, in their wake, a tragic array of broken, painful, and unresolved relationships. They are often identified by others as difficult or bad rather than impaired though the latter is a more accurate description. Although their struggle with relationships causes pain among family and loved ones, it also can be very painful for them. Imagine, for a moment, what it would be like to play a Bach concerto at a rock concert and then to have no idea why you're booed off the stage.

Because these disorders do wreak havoc with relationships, professional staff working with such individuals can find themselves feeling inexplicably drained, angry, frustrated, or unsuccessful. Caring for persons with personality disorders may result in polarization or triangulation within even the most tightly knit teams.

Returning to the narcissist example, patients who assume they are the center and the best may do quite well during hospital intake as everyone asks them questions and attempts to make them comfortable. Later, when they ring the call button every few minutes and expect immediate attention, they'll be quick to categorize staff as good or bad based on quickness of response. If staff members buy into this, they eventually will direct their frustration toward one another to the detriment of all concerned.

Likewise, patients with dependent personality disorders will be very content with staff more inclined towards excessive nurture, and aversive or passive aggressive toward others. Those with
avoidant disorders may react in an opposite fashion to these caregiver styles. All these are patterns that will not change; they need to be understood and worked with.

**Personality disorders and their characteristics**

Chart 1 (p. 12) gives thumbnail sketches of the ten DSM personality disorders, based on Lester’s material. While useful in providing an overview, these are obviously gross simplifications, and should not be given diagnostic authority. In reality, they often seem to overlap or fall into far less discrete formations. This chart includes Lester’s descriptions of how each disorder typically is experienced by others, such as neighbors, family, acquaintances, or fellow workers in language chaplains may well hear as they listen to loved ones or facility staff talk about these patients.

Chaplains frequently observe these traits in patients, only to watch them dissipate later on. After all, being stingy, wishy-washy, melodramatic, or forgetful is all part of what it means to be human, and none of us is immune. The term personality disorder becomes a legitimate categorization only if these traits persist with predictability over long periods of time and in a wide variety of contexts, remaining intact even when they obviously generate problems instead of solutions. Further, it is never a useful categorization if it is used to dismiss, discount, or otherwise diminish patients, and it is never to be used as an excuse to give up on them, though that may be very tempting at times.

To name the challenge, however, is worthwhile as it is best to know as much as possible about what we chaplains may be dealing with.

- These are often the patients that drive a staff to fury, virulent disagreement, or stony indifference; the ones we are called in to “handle” in hopes that we will somehow muster the patience and tolerance others have long since spent.

- These can be the patients that we try hardest to connect with, but who remain oddly immune to connection; the ones we wake up thinking about in the night, wondering why we couldn’t have done better.

- These are sometimes the patients whose rooms we secretly dread walking into: the ones in last place on our visit list, situated there in the unspoken hope that we won’t have time to get there.

- These can be the patients whom families complain about—even in the waiting room during surgery—patients who few people come to see or who seem completely friendless, whose connections to the broader community seem tenuous, superficial, or non-existent.

- These can be the patients who express an excruciating pain they cannot break out of, who describe over and over a world that is unjust, unfair, untrustworthy.

- These are the patients who are prone to extremes: wildly impulsive at times, then distant or even disassociated, then vehement when we wouldn’t expect it, then impulsive again.

- These are often the patients who seem to travel with a cloud of chaos around them, wherever they may go. They may already have passed through several other facilities, moving from place to place because of chronic dissatisfaction or because they’ve repeatedly been asked to leave.

Living with a personality disorder can be hard, not only for the patient, but also for involved family and staff.

Dying with a personality disorder can be hard too. Add to chronic rigidity and disturbed relationships, the elevated importance of both trust and hope in the dying process, and what may emerge is a high risk, chaotic, painful situation.

**What does this mean for spiritual care?**

Following are suggestions for chaplains who provide spiritual care to these special patients, their loved ones, and their caregiving staff. It is by no means a systematized or finished collection.

**Establishing trust**

Understand that you may not be trusted, and avoid self-critique if your normal abilities to connect and establish trust seem diminished. Perhaps you cannot offer a perfect harmony to the piano tone your patient is so persistently playing. In fact, count on it, but also assume that some degree of trust still is possible.

Consistency is very important here. Even if you can’t do exactly
<table>
<thead>
<tr>
<th>Disorder (DSM)</th>
<th>Disorder as commonly described by laypeople</th>
<th>View of others</th>
<th>Individual's View of self</th>
<th>Coping method</th>
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<tbody>
<tr>
<td><strong>Cluster 1 – Mature Type</strong></td>
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<tr>
<td>Paranoid: suspicious, distrustful</td>
<td>Takes everything personally, questions every motive or intention, gets angry or obsessed over small things gone wrong, blows everything out of proportion, seems thin skinned, “chip on shoulder,” seems vindictive, is spoiling for a fight.</td>
<td>Dangerous</td>
<td>Mistreated</td>
<td>Secretiveness</td>
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<td>Schizoid: socially distant, detached</td>
<td>Seems cold, aloof, blank or zombie-like, easily forgettable, impossible to talk to.</td>
<td>Uninteresting</td>
<td>Self-sufficient</td>
<td>Solitude or one strong interest</td>
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<td>Schizotypal: odd, eccentric</td>
<td>Seems weird, strange, eccentric, oddly anxious, inside own head, different, crazy, genius, full of odd non-sequiturs, confusing.</td>
<td>Boring, plain</td>
<td>Gifted</td>
<td>Eccentricity, grandiosity</td>
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<tr>
<td><strong>Cluster 2 – Immature Type</strong></td>
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<td>Antisocial: impulsive, aggressive,</td>
<td>Charming at first, untrustworthy later, sincere at first, duplicitous later, immature, self-centered, manipulative, dangerous, cognitively inflexible, rationalizing, haughty, contemptuous.</td>
<td>Suckers</td>
<td>Superior</td>
<td>Opportunism</td>
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<td>manipulative</td>
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<td>Borderline: impulsive, self-</td>
<td>Unreasonable, dependent, in chronic emotional pain, overly intense, vaguely threatening, dramatic, manipulative, runs hot and cold, inconsistent, frequently depressed or agitated.</td>
<td>Angels/Devils</td>
<td>Vulnerable</td>
<td>Emotional justification</td>
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<td>destructive, unstable</td>
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<td>Histrionic: emotional, dramatic,</td>
<td>Always seems needy, showy, superficial, melodramatic, seductive, shallow, childlike, overly body oriented.</td>
<td>Admirers</td>
<td>Fawning</td>
<td>Performing</td>
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<td>theatrical</td>
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<tr>
<td>Narcissistic: boastful, egotistical,</td>
<td>Always focused on self, selfish, presumptuous, demanding, uncaring, manipulative, demeaning, rageful, self-righteous, power mad, arrogant.</td>
<td>Servant</td>
<td>Special</td>
<td>Image management</td>
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<td>“superiority complex”</td>
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<td><strong>Cluster 3 – Anxious Type</strong></td>
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<td>complex”</td>
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<td>Dependent: submissive, clinging</td>
<td>Clingy, wishy-washy, fearful, manipulative, passive-aggressive, inviting exploitation, naive, desperate for caretaking.</td>
<td>Competent</td>
<td>Confused</td>
<td>Following instructions</td>
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<tr>
<td>Obsessive-Compulsive:</td>
<td>Stingy, perfectionistic, indecisive, cold or unemotional, hoarding, anxious, controlling, demanding, workaholic.</td>
<td>Contaminated</td>
<td>Righteous</td>
<td>Control</td>
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<td>perfectionistic, rigid, controlling</td>
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what someone else wants or needs you to, you can still be meticulous about what you say you're going to do. This does, over time, effect a dependable pattern of caring that a patient can comprehend as trustworthy. These patients usually don't tolerate well a casual phone call informing them that you have to cancel a visit. They may seem angry or highly distressed or brokenhearted, but at the root of it, they're probably scared. Death is scary, change is scary, and at some point the fear becomes hostility or frustration or panic. This is true for all of us, but often somewhat exaggerated for those with personality disorders.

If you do come to be unpredictable with these patients a time or two, forgive yourself quickly, and move on. Do your best to be as dependable as possible, and let go of the rest. Don't waste time attempting to persuade patients that you are trustworthy with words when your actions don't communicate an identical message. They typically pay acute attention to both and often expect you to fail. If you are bailed in volatile exchanges about trust or failure, deescalate as compassionately and as calmly as can.

I have failed to establish trust with personality disordered patients in one of two ways: by avoiding them, usually because I couldn't be what they wanted me to be and felt drained by that, or by losing calm in the face of their own distress dramas, inadvertently demonstrating that I am emotionally unpredictable after all.

If you have established trust, know that you may have provided something profoundly important. The life history of many personality disordered people is chapter upon chapter about trust broken, relationships torn or mutilated. To offer someone with such a history something even semitrustworthy to hold on to as life's end approaches is not trivial and can matter a great deal.

**Evoking hope**

A patient's personality disorder in and of itself has often provided a primary—if somewhat limited and limiting—source of hope for them over many years, e.g., "If I can just play my tune and everyone listens, I will be all right." Translation: "If people just pay attention, if they just respond to how [important, dependent, fearful, untouchable, afraid] I am, I will be all right."

To put this in theological terms, the disorder, functionally, has become a god. Like some old, inflexible, and relatively loveless deity, it has told them what to do for years. It probably has no name, so it can't be talked about easily, and that only increases its power. Those with personality disorders who are members of a faith community may speak about their faith in very plain and conventional terms, but what they are truly bound to—and bound by—is the disorder itself.

Whether one's personality is disordered or not, to lose one's God, the deepest source of focus and strength and internal organization, is to lose hope altogether. This is terrifying for anyone.

Some personality disordered patients describe unbelievable transformations regarding hope from inside the crucible of the dying process, breaking free and then regenerating spiritually with the lightening speed of conversion. Others seem to die as they have lived, playing the same tunes that have been their only themes for years.

As chaplains, we have an ethical obligation never to deconstruct or even significantly reframe self view or world view at this point in a patient's life, even with the plan of bringing forth a perspective we deem more hopeful or healing. As the patient's remaining time on earth is limited, there may not even be time for reconnection, especially for someone who has limited spiritual resources in the first place.

Many personality disorder patterns are so strong that we couldn't deconstruct them if we wanted to, even in the face of death. Yet we may experience pressure, perhaps from our own internal agendas, more likely from family members who desperately need something from our patient and see that time is running out: "Dad hurt me for so many years. Can't he apologize just once before he dies?" "My wife has left me and come back again so many times I've lost count. It's killing me that she can't tell me how she really feels before she dies." Such needs are hard to ignore. Even so, we best honor our personality disordered patients at this point by leaving whatever they cling to fully intact. However, this does not mean that hope is out of reach, either for patients or for their families.

**Utilizing life review**

Life review, the panoramic retelling of one's own story with opportunity for focus on selected details and events, can be very potent in generating hope for personality disordered patients at end of life. These are people whose limited
capacity for self reflection has led them to focus far more on the exterior world and its flaws than on their own inner workings. Often, others get tired of listening to them and find some excuse to get away.

It can be very helpful, and also soothing, for them to be well heard. As we provide an encouraging and supportive presence, ask questions about or highlight the more hopeful segments, point out patterns of resilience or redemption—no matter how fragmented—we help them to remember that life does have larger meaning. This implies that death does too.

Tradition, ritual and prayer

Patterned repetitions that feel familiar and safe also can soothe and comfort. For example, the obsessive-compulsive patient, suffering greatly from loss of control as the dying process progresses, may find deep relief in the repetitive reading of a single scripture passage. It is a touchstone, a sign that at least one thing is not in upheaval.

A patient with antisocial disorder told me he'd been raised in a mainline Protestant tradition, adding that this meant little to him, that he hadn't been to church in years. When he mentioned that he was one-quarter Cherokee, I asked if he would like to explore that tradition a little more, and he said he would.

In our very first round of learning, he came upon an illustrated description of a warrior and recognized immediately the positive manifestation of his own disorder. Like a warrior, he too was fearless in battle, willing to take on any enemy. Like a warrior, he too was proud, and possessed superior strength and agility. Like a warrior, he too loved to win but also was capable of surrendering with great dignity.

He used this image from his own lost heritage to guide himself through the dying process. It provided him with an ideal, a way of picturing how to proceed, how to deal with physical suffering, how to let go when the time came. My only tasks were to bring him more information and to listen as he worked his way through it.

He never apologized to the wife he'd hurt very badly and never received visits from the children who'd come to hate him, but at least he knew he'd die like a warrior, and this brought him considerable peace of mind.

Supporting loved ones and facility staff

Chaplains whose pastoral care includes families, loved ones, and even facility staff may come upon significant chaos and pain surrounding personality disordered patients. It is not uncommon for much to be left undone. The final gifts often cited in hospice—I love you, I forgive you, I ask for your forgiveness, and I release you—simply remain ungiven. They are gifts that many people with personality disorders can’t pass out. They often see no need for reconciliation or wish to avoid it at all costs. They may be unable to provide the kind of self-reflection that others feel strong need for at such times.

This means that spouses, children, friends, and loved ones may end up with a lot of unfinished business. Not at all uncommon are unexpressed anger and resentment, a strong sense of disconnection, or tremendous guilt for having failed, despite Herculean effort, in what they consider a primary relationship.

Earlier struggles, which quite likely have occurred with their personality disordered relative, may have resulted in spiritual and emotional growth, and inspired them to seek out new supports. If this is not the case, we chaplains can at least give them a useful framework from which to process their loss. For example, we can normalize and affirm their struggles and point them toward means of support, e.g., individuals, groups.

Staff may reveal to you that they have given up, made some big mistakes through loss of perspective, or become frustrated with one another. Again, we as chaplains can provide helpful affirmation and normalization. These patients can be very difficult to work with. If we enter into their drama by blaming ourselves or one another, we lose effectiveness.

Staff can spell one another at points of exhaustion, habitually interact with the patient in pairs, draw up a clear list of expectations and consequences, communicate clearly about attempts at polarization, and practice cheering one another on. We can offer encouragement, non-judgmental listening, and affirmation. Last, but far from least, a bit of humor often provides much needed release.

Conclusion

Most human beings, when told that their condition is terminal, experience profound spiritual vertigo. A monumental shift in perspective is called for as their whole lives undergo a sea change. Fear, anger, numbness, denial, bargaining—all the phases Kubler-Ross so elo-
quently described for us—are part of a challenging journey to final acceptance, a journey that involves massive adaptation to a new reality.

For patients with personality disorders, who struggle greatly with both self-reflection and adaptation, this journey may seem impossible. They may lock on to the phases most aligned with their disorders, denying that they are dying at all or expressing so much fear that loved ones become enslaved in attempting to reassure them at all costs. Alternately, they may proceed with full dignity and grace, depending upon how well their individual player piano tunes suit their particular circumstances. In any case, we need to honor who they are, rather than focusing on who they can, or cannot, become.

Perhaps most helpful of all is simple acceptance of how insurmountable this process of radical adaptation can seem to them. Just as we don’t expect patients with chronic obstructive pulmonary disease (COPD) to engage in activities that leave them desperate for breath, we should not expect large amounts of flexibility from patients with personality disorders. We encourage them to do their best toward achieving that delicate balance of self-empowerment and surrender that lends them the greatest possible spiritual comfort. We invite them to seek out, to name and to be supported by all sources of hope and trust, and to rest in these.

As their dying progresses and mobility, consciousness, and communication diminish, their loved ones may experience more acutely than before the painful realities of unresolved negative emotions. We can assist them, in turn, by offering simple comfort and affirmation, helping them to be realistic, and to normalize their own feelings as much as possible. To the extent that these same difficulties plague our colleagues and fellow staff, we can offer extra support to them as well.

References


5. Lester, Personality Disorders, 16-7.


Lester, Personality Disorders, 28-83.